

Very Late Diagnosis of Asperger's Syndrome 2013 UK Survey Report



Prepared by Philip Wylie and Sara Heath

Very Late Diagnosis Of Asperger's Syndrome
2013 UK Survey Report

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www.shropshireautonomy.co.uk/publications/survey-reports/VLDAS2013

<http://philipwylie.com/publications/2013-uk-survey-late-diagnosis-of-as-adults>

Foreword by Philip Wylie

During December 2011, while I was living in Cambodia, I was browsing through my professional Accountancy magazine and I encountered an interesting article about autism. The article - written by fellow Chartered Accountant, Mark Lever, CEO of the National Autistic Society – reflected an inescapable and inconvenient truth.

After reading Mark Lever's article, I was reasonably sure that I have Asperger's syndrome, so I immersed myself in the research of anything related to autism. In July I contacted Sara Heath of Autonomy (Shropshire) and I booked an Asperger's syndrome assessment with her, which was conducted via video using Skype. On 22 July 2012, Sara emailed to me a positive assessment of my "Aspergic" condition.

I left the UK a decade ago in February 2003 to live in Northern Thailand because I was unable to support myself in my home country. I have been writing, editing and consulting. I suggested to Sara that we jointly conduct a market survey about the lives of adults with Asperger's syndrome who were diagnosed late in their lives. Sara agreed to the project.

Sara has been responsible for collecting all the information from Autonomy's extended membership. I, on the other hand, designed the survey questionnaire, compiled the data, analysed the information and produced this report. So, this project is a joint mission, and all proceeds will benefit people who are on the autism spectrum.

I have not ceased to be impressed by Sara's steadfast focus towards this project, while she has mentored hundreds of autistic people (including myself). Sara Heath is excellent at her job, and I am grateful for her support. In particular, Sara is extremely truthful-yet-diplomatic, and I have learnt a lot from her.

Thank you for investing in our project and supporting Autonomy Plus.

Philip Wylie MSc.
Chiang Mai
18 February 2012

Forward by Sara Heath

I have been working and volunteering in the field of autism - primarily with people who have learning disabilities - for over 40 years, and I am passionate about the subject. Recently I become aware of the needs of able people on the autism spectrum, so my niche is in the support of these individuals. I have firsthand and personal experience of this, as my adult son Eric has a diagnosis of Asperger's syndrome.

Eric and I set up Autonomy in 2004 to provide low-level preventative support for people on the autism spectrum. Later we became a self-help and social group because our members support each other at our regular social events. Autonomy is independent and self-funded, so we have developed our unique way of financing our services.

Voluntary groups like ours help people with autism and Asperger's with recognition, advice, advocacy and mentoring while navigating the diagnostic pathway; so we established AutonomyPlus for the provision of pre-diagnostic assessments, training and help with access to welfare benefits. We promote our services on our website, which is primarily for local people, so we were surprised to receive a query from Phil when he was living in Cambodia last year, requesting our help and support! Now we are proud that Autonomy is now known internationally!

I would very much like to thank Phil for the suggestion of collaborative work, which has been a challenge, due to the nature of our client group, but well worth the effort. I am delighted, however, to have been asked to help with this fascinating study on very late diagnosed individuals, and thank all the Autonomy members from around the country their involvement in this survey and for their honest answers.

Sara Heath M.Ed
Shrewsbury
18 February 2013

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EXECUTIVE SUMMARY

Adults with Asperger's syndrome and high ability autism are not supported adequately in the United Kingdom, and as a result, their life quality is so poor that 80 percent of our respondents are suicidal and 50% of them engage in some form of self-harm.

Every Adult with Asperger's syndrome in this survey suffered mental ill-health due to their late diagnosis of Asperger's syndrome and lack of appropriate support. Mental ill-health includes anxiety, depression, insomnia and stress.

45 percent of the survey respondents had been misdiagnosed before they received their correct diagnosis (or assessment) for Asperger's syndrome. The later the adult with Asperger's syndrome receives appropriate diagnosis and support, the more complex the personality disorders become.

There are other reasons for widespread misdiagnoses. For example, many General Practitioners (GPs) and psychiatrists who are qualified to provide a formal opinion relating to autism have minimal knowledge, training, and experience in this area. Who would know more about Asperger's syndrome than a full-time Asperger's syndrome specialist practitioner?

Inevitably, the happier adults with Asperger's syndrome lived with their children or relationship partner, and earned a living from their area of interest in a supportive (inclusive and non-judgmental) environment. However, only 15 percent of the respondents were in paid employment, matching national statistics published by the National Autistic Society.

We know that autism is inherited genetically and that there is no cure for this condition, and there probably never will be. Therefore, we do not support research foundations that wish to find a 'cure' for autism. Neurodiversity is healthy, and having differences among the human population makes the world more interesting. The ultimate panacea is tolerance and acceptance of differences in our population, rather than eugenics, cloning or forcing people to behave the same way.

INTRODUCTION

Sara Heath invited all survey respondents to complete the survey questionnaire, which was designed by Philip Wylie. All respondents were resident in UK during the period of the market survey (from 20 October 2012 until 16 February 2013); all were national members of Autonomy, Shropshire.

This market survey report is based upon the analysis of twenty completed survey forms, which were completed by telephone or returned via email or ordinary post. Sara Heath was responsible for collecting all the information from Autonomy's membership.

Profiles of each of the twenty respondents are summarized in Appendix 1, but all names have been changed to protect their identities. Sara and Philip are particularly grateful to all of the respondents for sharing their experiences, and enabling us to compile this report.

Although the sample size of this survey is relatively small, the statistics and conclusions are representative of the autism community in the UK. Most importantly, the respondents have Asperger's syndrome. None of the people surveyed had their diagnosis of AS subsequently quashed, and the majority (65%) of them had obtained a formal diagnosis by a psychiatrist.

Why are there so many undiagnosed adults with Asperger's syndrome out there? Unfortunately, the publications relevant to Asperger's syndrome were translated into English in the early 1980s and the diagnostic criteria was developed in 1994, so those people with AS who were still undiagnosed by the age of 33, 'missed the boat'. Simon Baron-Cohen's article provides a succinct summary at the following website link:

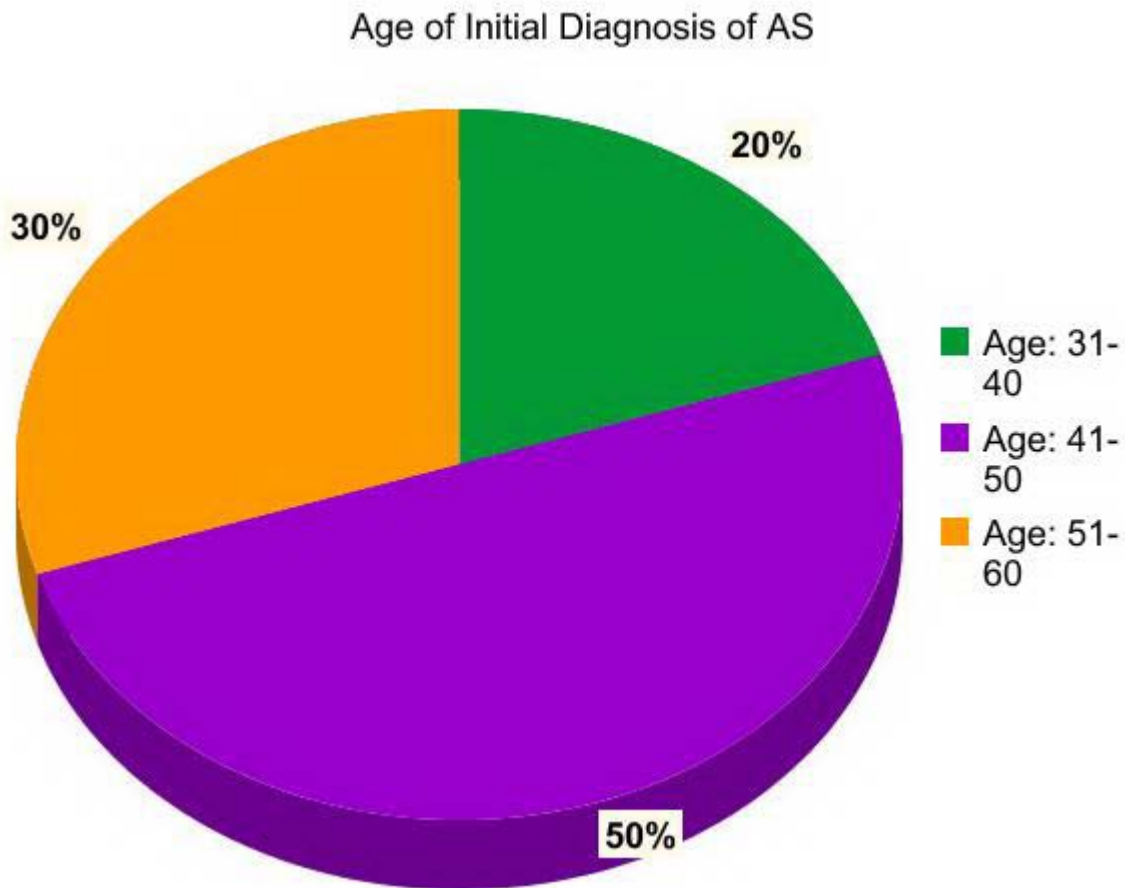
http://www.iancommunity.org/cs/articles/very_late_diagnosis_of_asperger_syndrome

The author, Philip Wylie, has another agenda for conducting this joint survey; as a late-diagnosed person, he wants to know whether the UK offers adequate support for autistic people. The answer to this critical question, will determine whether he returns to UK or stays in Southeast Asia for the remainder of his life.

DATA ANALYSIS

Gender and Age

The average age of diagnosis among respondents is 46-years-old. The survey respondents were diagnosed between the years, 2002 and 2013.

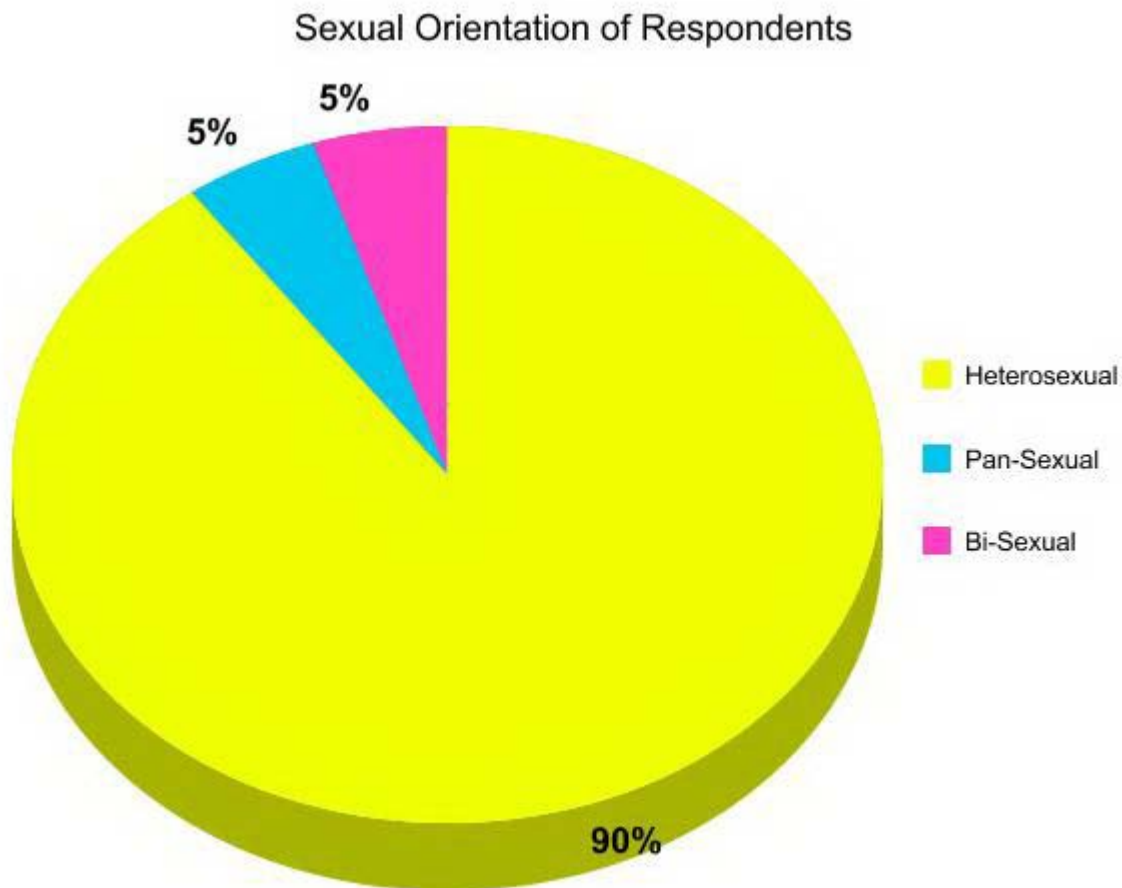


On average, the respondents completed this survey one and a half years after their AS diagnosis.

20% of the survey respondents are female; so four times as many men were surveyed compared to women.

Sexual Orientation

90% of respondents in this survey are heterosexual. The remaining 10% comprises one bisexual and one pan-sexual (or omni-sexual) individual.



Children

30 percent of the survey respondents have children, and just one out of six of these parents are currently in a relationship. These adults became parents after their AS diagnosis.

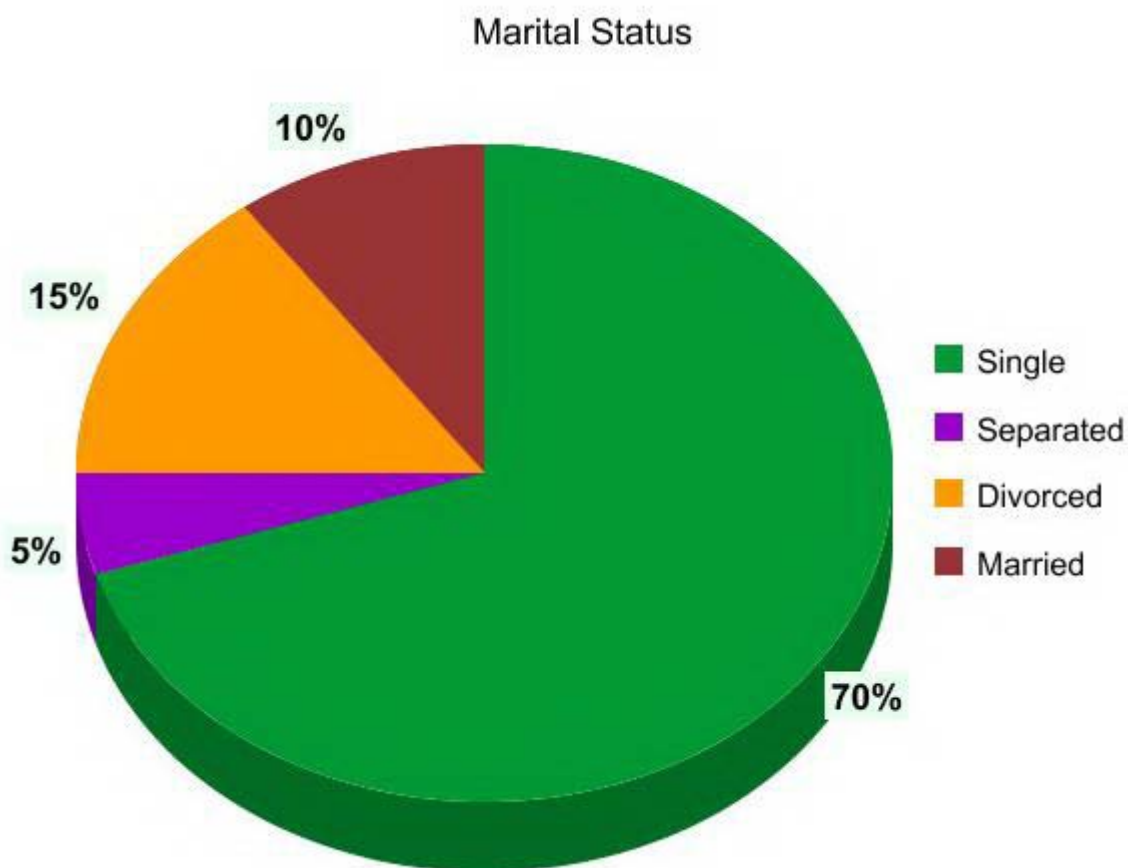
Some of the respondents became aware of their Asperger's syndrome condition when they discovered that their children are autistic. For example, Carol-Anne's 15-year-old daughter was diagnosed as having AS and Pathological Demand Avoidance (PDA) in August 2011; she also suspects that her youngest daughter, aged 13, has autism, as well as having learning difficulties; and her 8-year-old son is currently being assessed for Asperger's syndrome and PDA.

Sadly, there are still many people who believe that autistic people should be sterilized, or otherwise disallowed from having children. However, many adults with

Asperger's syndrome have nobody to talk with, or get help from, apart from their son or daughter. It is common for parents and relatives of autistic people to abandon them because they do not want to be associated with the toxic stigma of autism.

Children with autism often receive much more support than adults, and they should be able to lead a good life if society does not vilify them for being different. From our survey we found that the adults with Asperger's syndrome who have contact with their children tended to be happier and less isolated than those without.

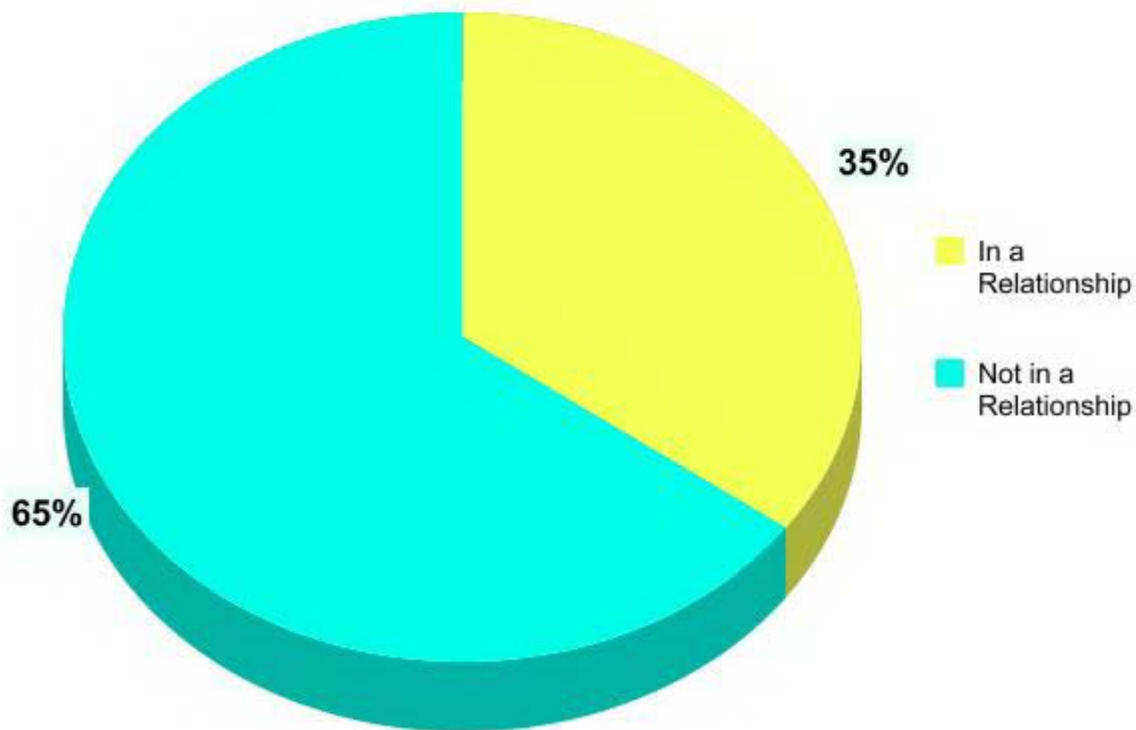
Marital Status



70% of survey respondents claim to be single; 5% separated; 15% divorced and 10% married. However, just over one third of the respondents were in a relationship at the time of survey.

Most adults with Asperger's syndrome have difficulty sustaining relationships, and there are many reasons for this. Lack of cognitive empathy causes Aspergic individuals to misunderstand other peoples' thoughts and feelings. It is also difficult for many autistic men to fulfill the stereotypical male role as family provider as just 15 percent of adults with Asperger's syndrome are in paid employment.

Relationship Status at Time of Survey

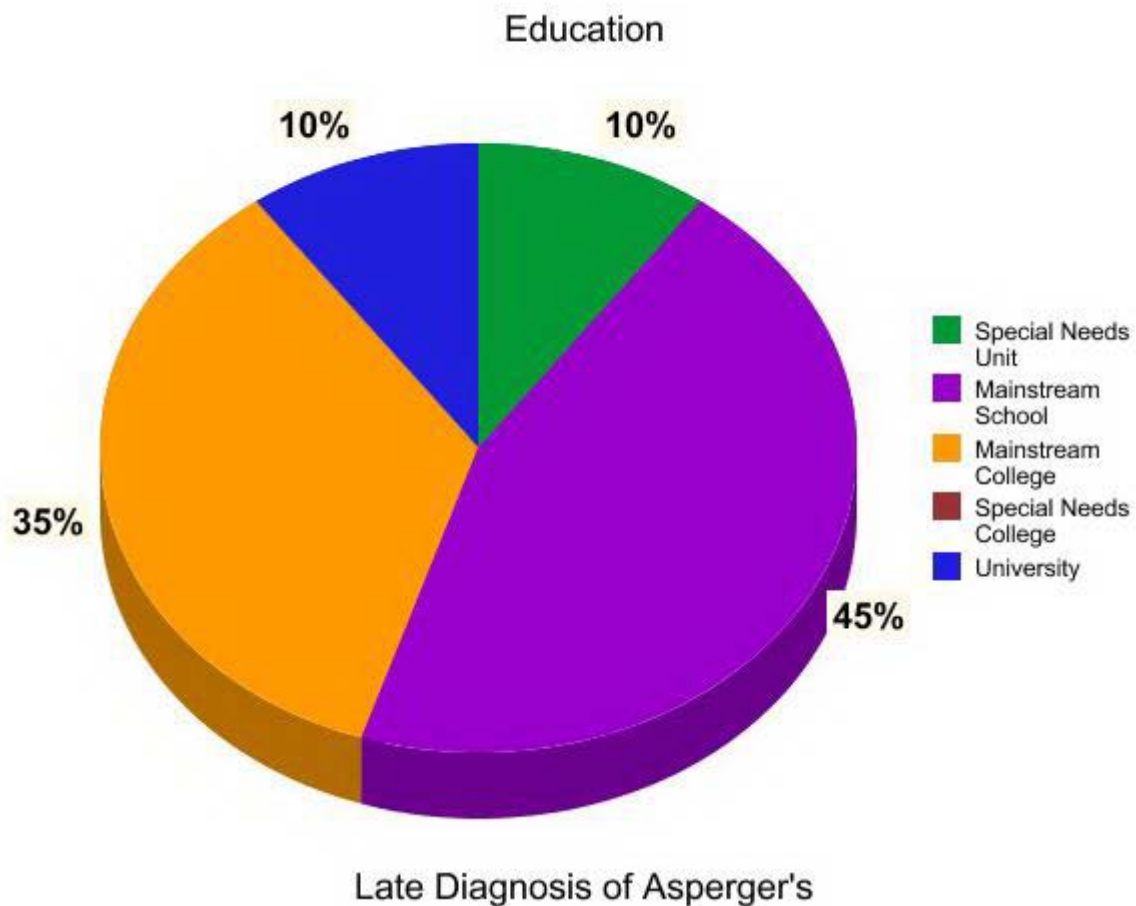


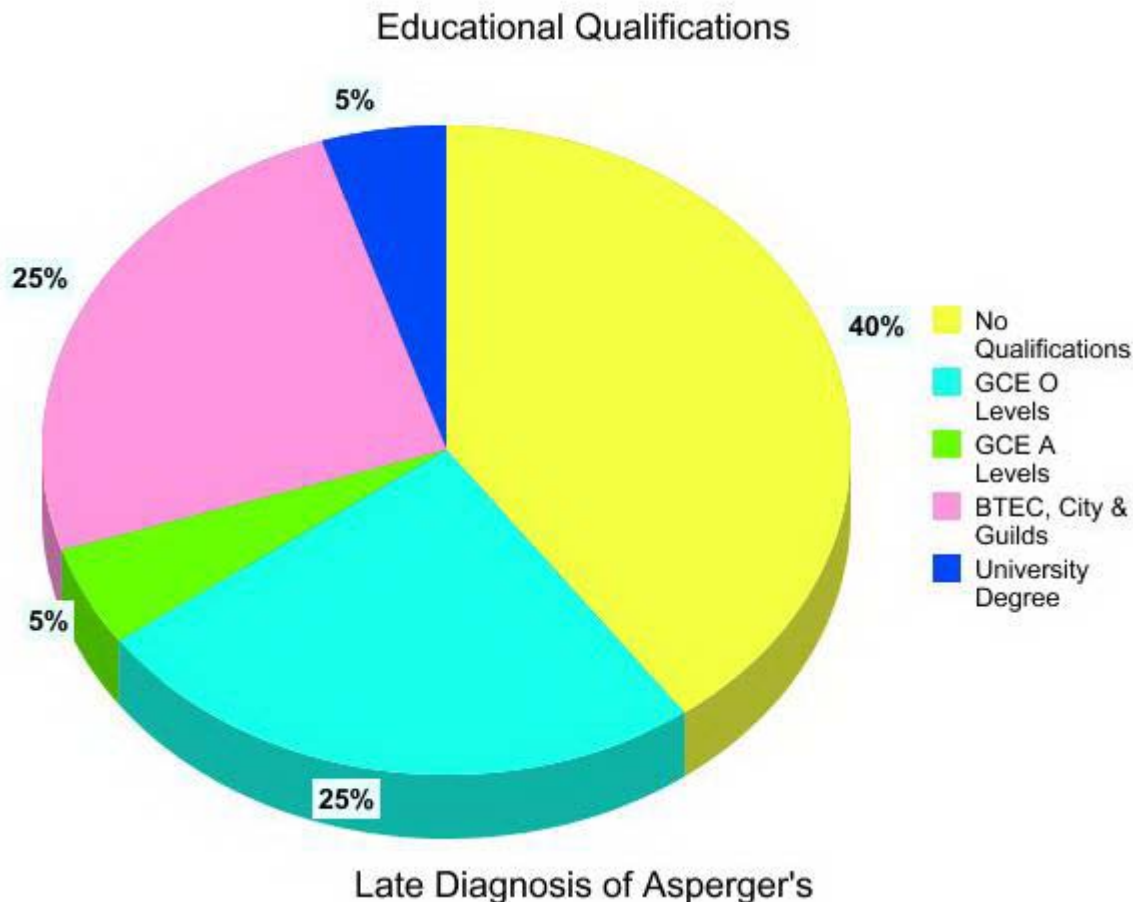
Most adults with Asperger's syndrome have a checkered history of broken relationships. Some of the respondents had never experienced a successful relationship with a sexual partner.

Education and Qualifications

45% of the individuals interviewed attended mainstream schools, and 35% went to college. 10% of respondents attended special needs units. The remaining 10% attended university.

The following charts show the highest level of education attained by the survey participants.





Considering that adults with Asperger's syndrome tend to have above-average intelligence, it is interesting that 40 percent of respondents have no qualifications whatsoever. One of the respondents was unable to read or write, so the individual was interviewed orally. Lack of diagnosis and appropriate support may account for the relative underachievement (academically and in their careers, if applicable) of respondents.

Employment and Finance

Three quarters of the survey respondents were receiving either a pension, disability or other benefits. 35 percent of respondents were working – in salaried employment, voluntary work, or part-time self-employment - at the time of the survey.

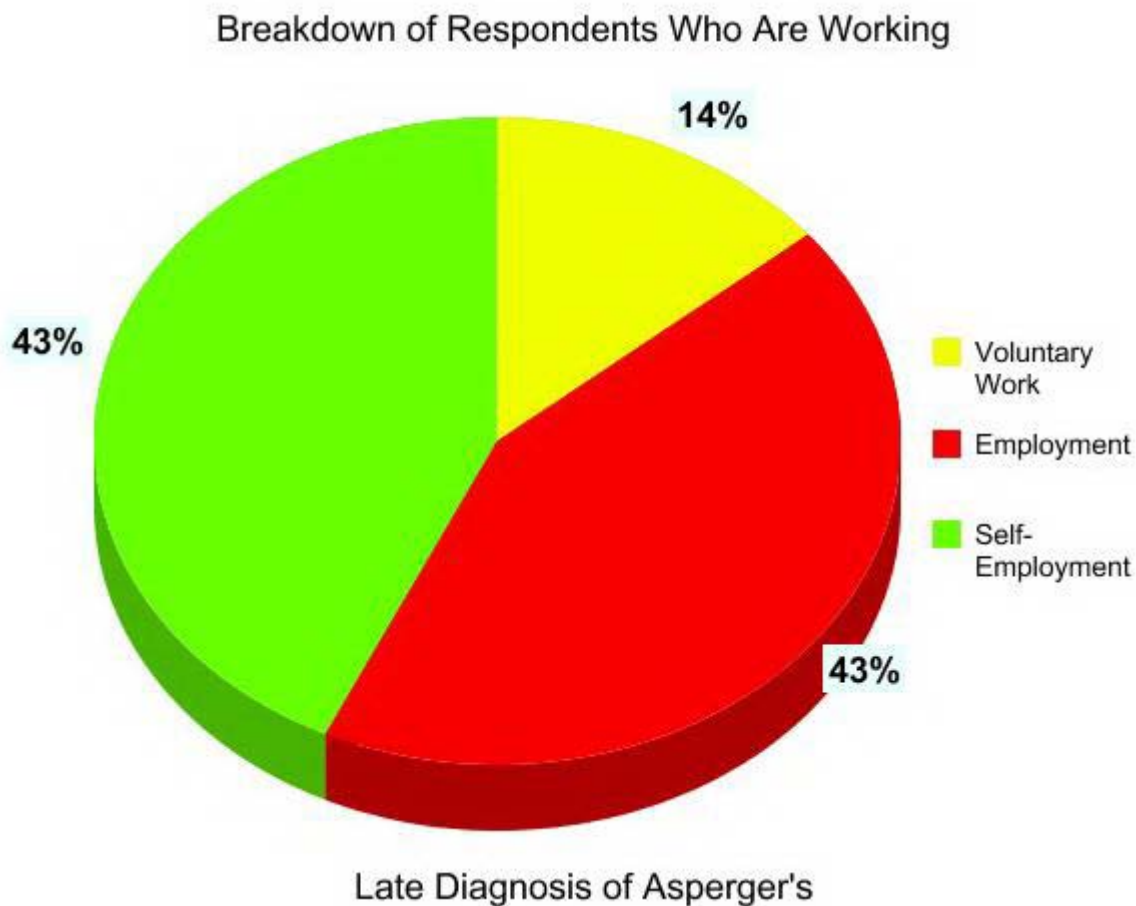
Every person in this survey had worked at some point in his or her life. However, bullying, stress and adverse office politics had prevented many of our adults with Asperger's syndrome from sustaining their employment.

“If I wasn't a carer for my daughter, I would be forced to work but it is so hard. I now know why I was so ill before I had my first child – stress and anxiety.”

- Carol-Anne

Mark Lydon, who has anger management issues, says, “I have worked as a cleaner, gofer, tried spraying engines and machines, sweeping floors and emptying bins until I argued with the bosses, so they let me go. I nearly hit one of them.”

Most adults with Asperger’s syndrome are peaceful and are rarely violent. However, Mark Lydon is understandably extremely angry about how society treated him, and especially the mental health system, which misdiagnosed him. However, Mark is feeling happier now that he has received a valid diagnosis for his Asperger’s syndrome because people understand him better, especially his mother.



15 percent of the interviewees lived on their salary from paid employment. The National Autistic Society cites 15 percent as average for people with Asperger’s syndrome in employment. The jobs undertaken by survey respondents are telephone engineer, IT coder, and fulltime security work.

15 percent of respondents were self-employed in the following capacities: dyslexia trainer and consultant, accountancy services, and a retail food business. Self-employment benefits people with Asperger’s syndrome if they can choose their working hours, and work in their area of special interest.

One of the respondents works as a fulltime volunteer in his area of special interest.

The data collected clearly shows that the individuals with Asperger's syndrome who were working were happier than their unemployed counterparts were.

Social Support Services

As expected, many of the respondents' parents were not alive, but some receive assistance from Mental Health and AS Support workers. Joining a local autism support group enables many adults with Asperger's syndrome an opportunity to connect with like-minded people.

Two of the respondents were arrested by the Police, referred to Social Services and subsequently received diagnoses for Asperger's syndrome. For example, Peter North was arrested for harassment and stalking a woman who he thought was his friend (an example of impaired cognitive empathy, resulting in his misunderstanding of other peoples' thoughts and feelings).

Ben Smith claims that he was set up and blamed for an offense that he did not commit. He says he was naïve and gullible, so now Ben has a criminal record.

Hobbies and Interests

As expected, the range of respondents' hobbies and interests is extremely diverse, spanning crabs and fish to creative writing, astronomy, and mycology (the study of mushrooms and fungi).

The two most popular categories in this survey are Science & Technology and Research into Special Interests. 30 percent of respondents stated their interest in these two categories. The category, Science & Technology includes technology, gadgets, mathematics, and astronomy.

The special interest subjects in this survey include the Knights Templar, the essence of Goth, mycology, veganism, money and finance, post-Apocalyptic survival methods, and dyslexia.

In our survey, individuals with Asperger's syndrome tend to love pets, wildlife and nature (including gardening, horticulture and fishing).

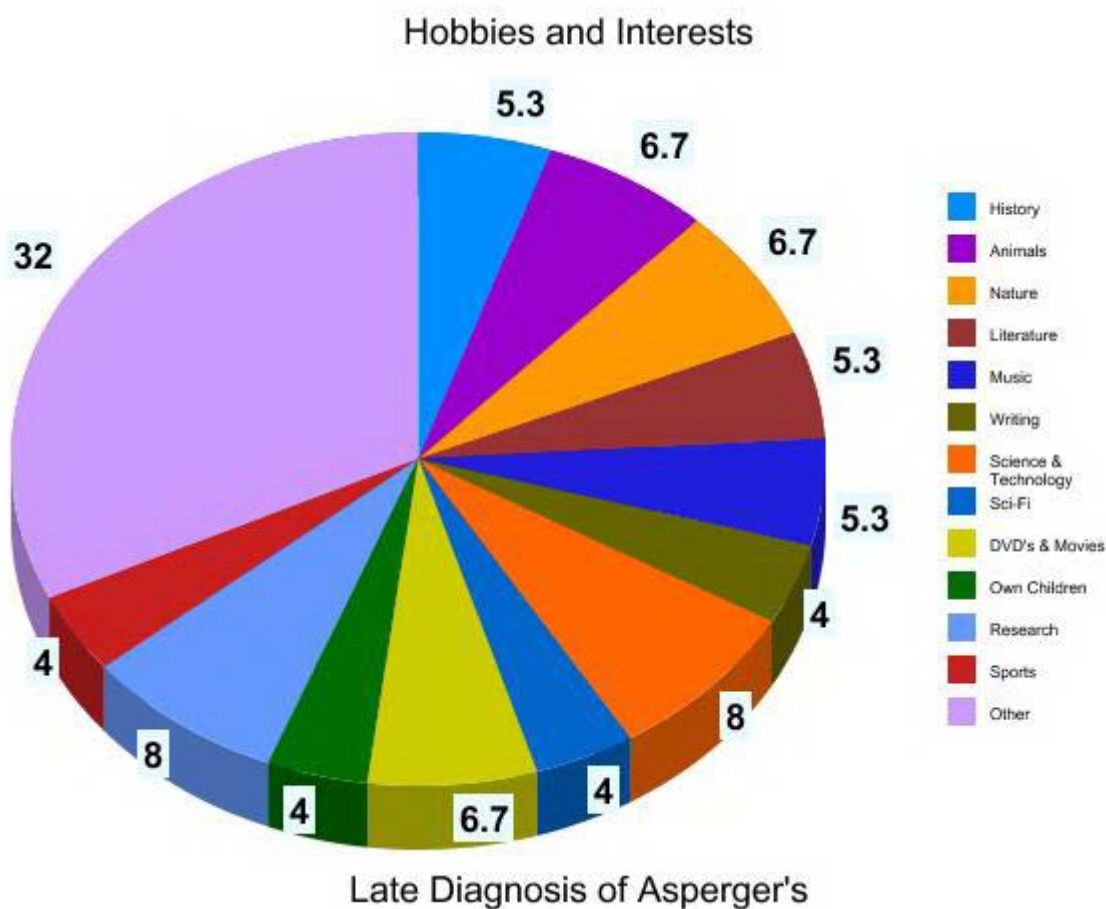
20 percent of the survey respondents have an active interest in ancient or modern history and archeology.

20 percent of the respondents enjoy poetry and literature. The category for Writing includes creative writing and wordplay, which is a popular pastime for many people with Asperger's syndrome. An example of wordplay is 'Global Evil-ution and Devil-opment' by reference to the words, Evolution and Development.

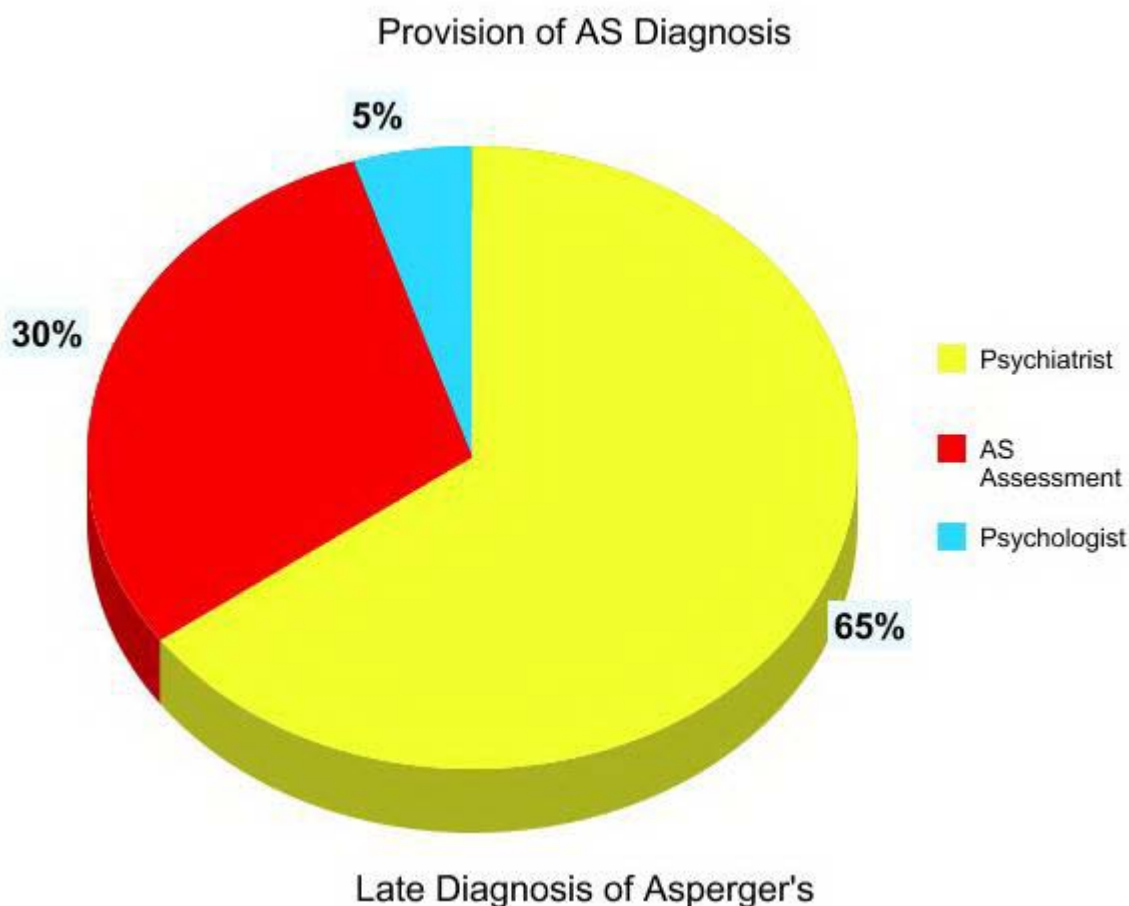
Most respondents liked DVD's and movies which specifically includes comedies and spy dramas.

The largest category, 'Other', includes art, photography, psychology, documentaries, educational programs, collecting watches and other old things, reading comics and books, walking, yoga, travel, football clubs, travel, cars, cooking and 'hiding from people'. Just one of the respondents said he liked to go out to public meeting places for drinks.

The graph below is divided among 75 hobbies and interests relating to the 20 respondents. Therefore, each respondent stated an average of 3.75 hobbies or interests. The numbers in the graph are percentages.



DIAGNOSTIC PATHWAYS



Over two thirds of the survey respondents have a formal diagnosis of Asperger's syndrome by a registered psychiatrist. 30 percent of the remaining respondents have a positive AS assessment from the specialist worker at Autonomy, and some are on the very long NHS waiting list for a medical diagnosis. None of the respondents had their AS diagnosis or positive AS assessment subsequently quashed.

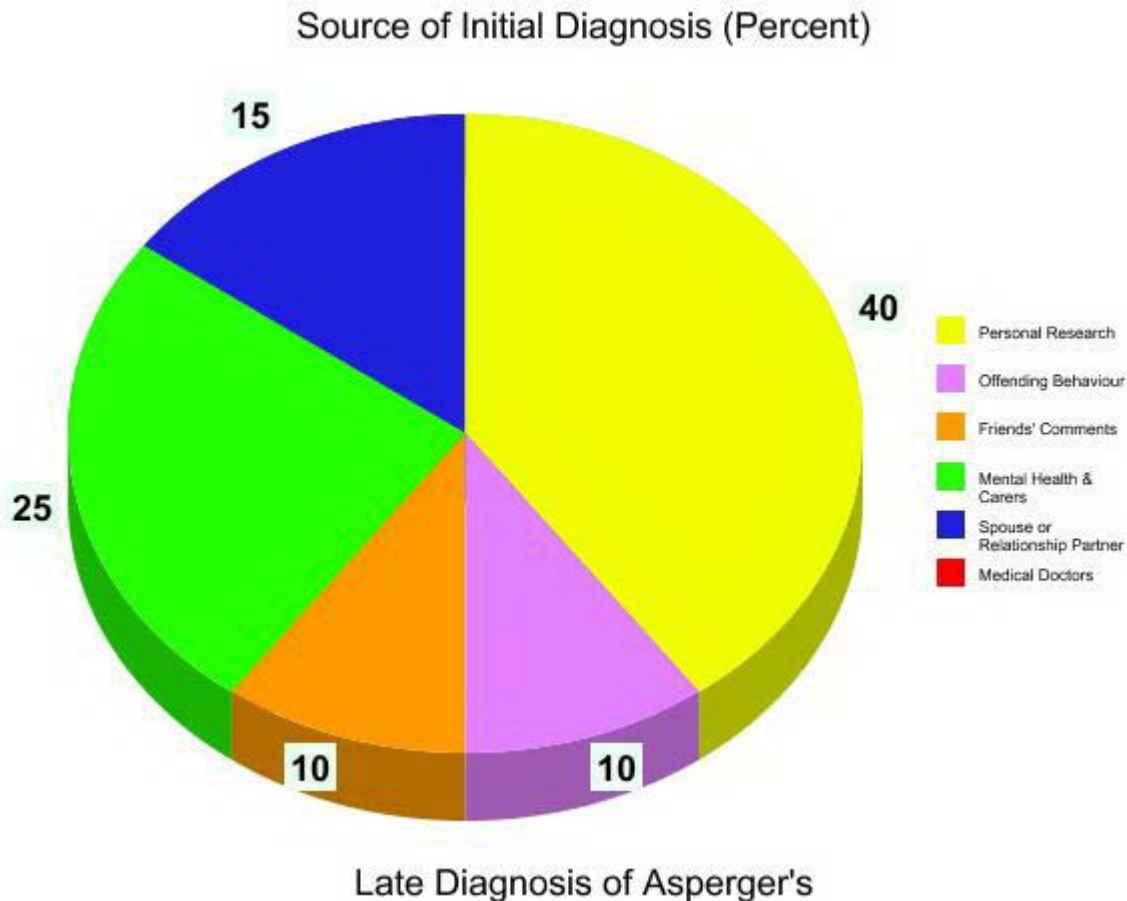
Ironically, a comprehensive and detailed pre-diagnostic assessment for Asperger's syndrome by a respected full-time autism practitioner – such as Sara Heath – we feel can often be more accurate than a formal diagnosis by a psychiatrist who may just have a few hours training in the field of autism, and few clients with this condition.

Due to lack of NHS funding, it is common for many adults to have to seek and pay for their own diagnosis privately, which may cost upwards of GBP600. A newly diagnosed individual then has evidence of expert '**opinion**', but which may change if s/he is seen later by another mental health professional.

The best way to identify a suitable autism practitioner who is qualified to provide diagnoses is to ask other people with autism, and to read publications written by the

practitioners. Some people prefer to consult with fellow Aspergic people, while others value their practitioner's empathy and integrity.

Initial Source of Diagnosis



In this survey, there were no cases of medical doctors initiating the AS diagnostic process. Over two thirds (65%) of the people surveyed discovered their condition on their own, or via comments by their spouses, relationship partners or friends.

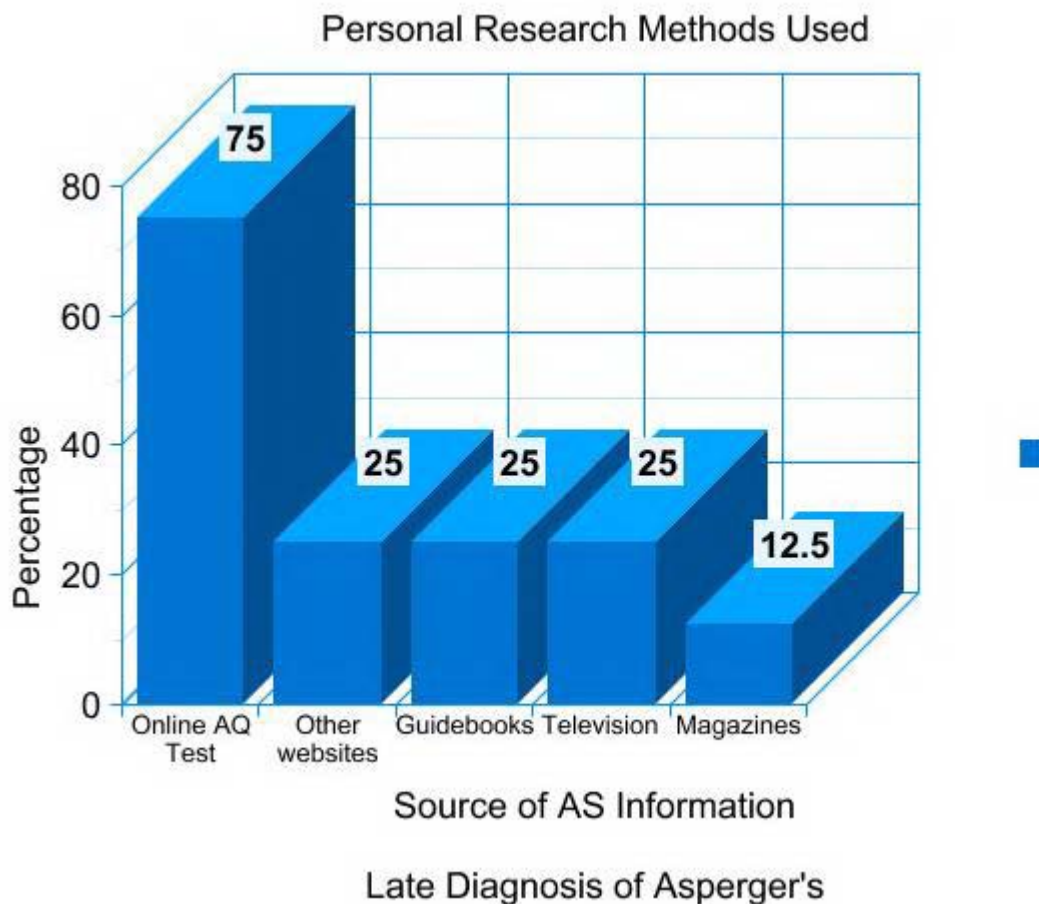
“My girlfriend told me that I am not right (normal) ... She knew that I’m different but she did not know it was autism.”

- Phil Downing

37.5% of respondents who self-diagnosed their condition via personal research did so after discovering that a close relative is on the autism spectrum. For example, Alan Ray began his personal research into Asperger's syndrome after he discovered that his nephew has the condition. Alan says. “I hadn't actually considered it until I started reading about it because my nephew was diagnosed, but once I knew a little, the conclusion was inescapable.”

Some parents question their own personality after their son or daughter is diagnosed as having Asperger's syndrome, but it is common in our survey that many distance themselves from the genetic issue.

Self-Diagnostic Methods



Some of the respondents used multiple reference sources to research their AS condition, such as the online AQ (Autism Quotient) Test, other websites and relevant television programs. For example, the AQ Test is available on *Wired* magazine's website. One respondent discovered his AS condition after reading a relevant article in the *Kerrang!* rock music magazine.

The following list shows how each of the twenty respondents discovered their Asperger's condition:

1. Personal research (AQ test and a relevant book)
2. Spouse's suggestion
3. Personal research (AQ test, other websites and television)
4. Personal research (by reading a book)
5. Spouse's suggestion (because their son has AS)

6. Offending behaviour lead to diagnosis
7. Friends' suggestion
8. AS Worker's suggestion (Social Services)
9. Mental Health meeting (Social Services)
10. Article in a rock music magazine
11. Personal research (AQ test)
12. Counselor's suggestion (Social Services)
13. Friends' suggestion
14. Referral by Police to Social Services
15. Personal research (AQ test)
16. Social Services (due to previous misdiagnosis)
17. Personal research (AQ test and other websites)
18. Personal research (AQ test and television)
19. Spouse's suggestion (following misdiagnosis)
20. Assessment by parents' carer

It may be concluded that undiagnosed adults with Asperger's syndrome will often miss any official autism screening procedures, and consequently they are left alone to identify the source of their confusion.

Self-Denial of AS

25 percent of the adults in this survey claimed that they denied their AS condition. This is understandable considering the prevailing toxic stigmas relating to disabilities and that nobody wants to see himself as being broken in any way.

[“Yes, it was difficult to come to terms with this fact.”](#)

- Robert Henley

Nowadays, there is more information available about Asperger's, and the media is more sympathetic towards disabled people. However, older people have usually internalized many of the negative stigmas relating to autism, so they find it more difficult to accept their new identity. Another problem with 'coming out' is that Asperger's is diverse (and therefore complex and easy to misdiagnose) and many people will doubt a person's diagnosis (which can be frustrating) as they 'look normal'.

[“I put my head in the sand.”](#)

- Debra Williams

[“I fear the stigma because I have been in the Mental Health Services....”](#)

- Ben Smith

“The feelings of maladjustment are so prevalent in a late diagnosis that, in a way, you are too scared to believe it.”

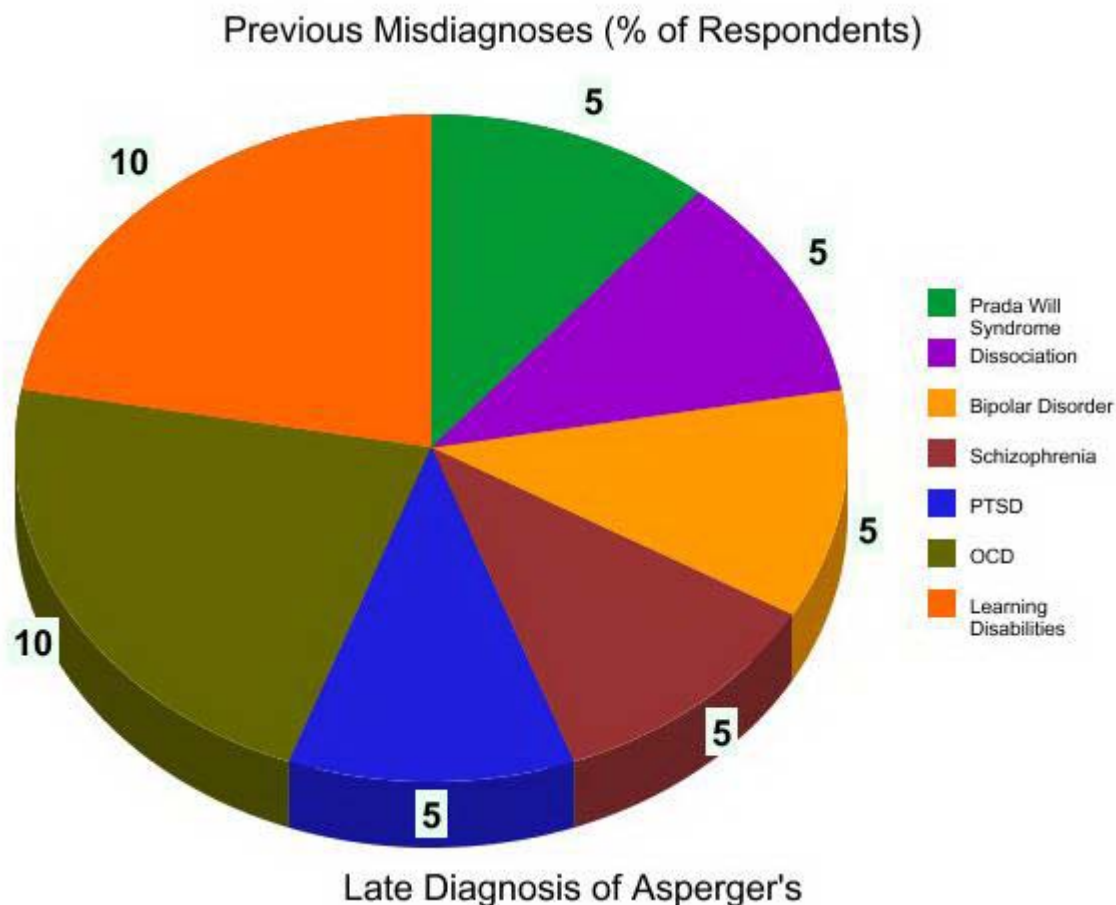
- Carol-Anne

“For a long time I felt things would be better if I could ‘just pull myself together’ but unfortunately this increased my feelings of depression and anxiety because I was putting on a front and trying to mask my symptoms.”

- Fred Smith

Misdiagnosis

45 percent of respondents had their AS condition misdiagnosed previously. A breakdown of the misdiagnoses follows:



“My GP said that I may have OCD (Obsessive Compulsive Disorder), so I looked into it and realized it wasn't, and that it may be Asperger's syndrome.”

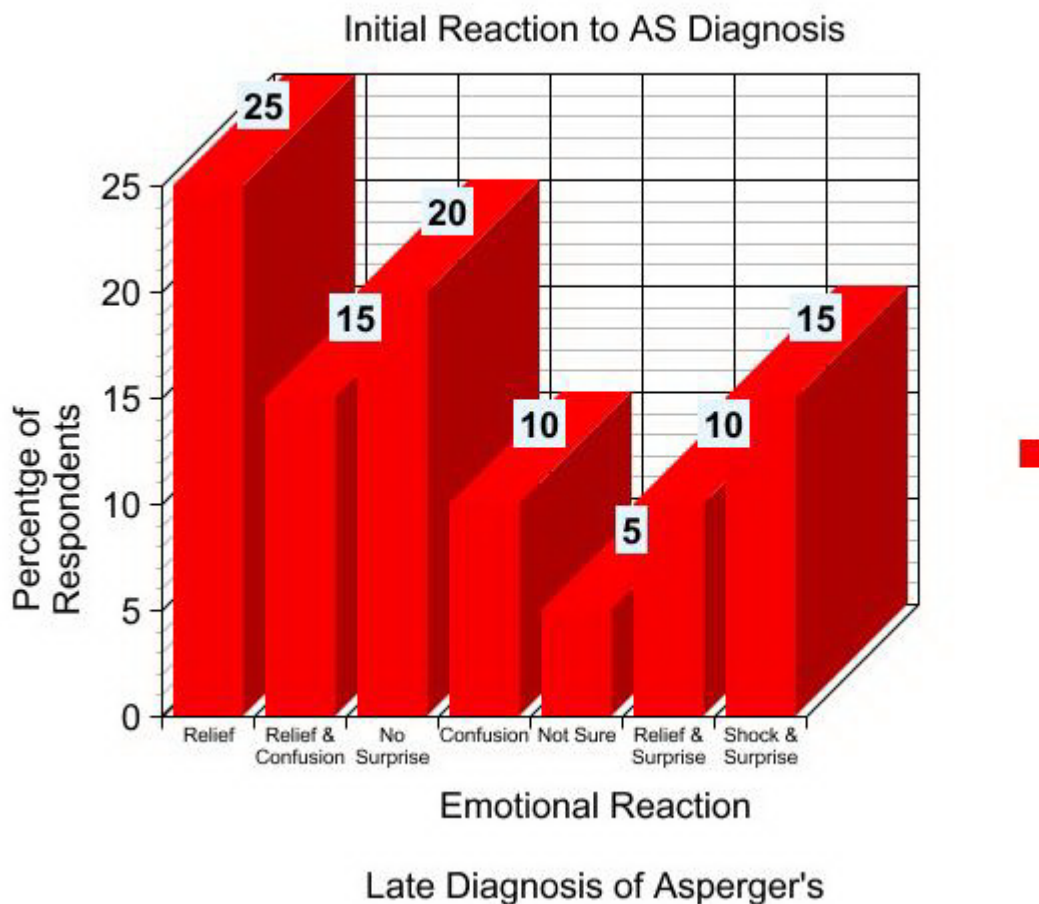
Many GPs and psychiatrists are poorly equipped with knowledge about autism, particularly in the case of co-morbid Asperger's adults because they are 'general'

practitioners rather than autism specialists. Therefore, most undiagnosed adults who have AS are left alone to identify the source of their issues, using online media and chance encounters with perceptive friends or relationship partners.

“I did not know I had autism. I was beaten up all my life, so it has been really hard for me. I was told that I have schizophrenia, and I believed them, so I went to a mental hospital where I had to take medication. I was also told to take anti-depressants for SAD,” says Mark Lydon.

Fred Smith is currently waiting for his GP to refer him for a formal medical diagnosis. “This depends on funds being made available by my GP/NHS Trust. This delay has made me reticent to return to my GP because without a formal diagnosis because I worry that I will be treated as someone with depression, anxiety and so on, rather than these conditions arising as a consequence of my Asperger’s syndrome.”

Reaction to Diagnosis



20 percent of the survey respondents reported no surprise when they received their AS diagnosis because they already suspected it. However, Jennifer Marks said she was shocked when she received her AS diagnosis even though she already suspected

it.

Harry Lloyd commented that ‘The light bulb turned on’ and he felt happiness and relief when he received his AS diagnosis.

“I knew I was not right, but didn’t know why,” says Phil Downing

John Carlisle said that he experienced relief, confusion and anger simultaneously after his AS diagnosis because he suspected that he would not now be able to receive adequate support from the NHS.

Chris Stevens, who experienced relief and confusion afterwards, said he needed some time to get used to his new self-identity, but the diagnosis made sense and he can live with it.

A key advantage of diagnosis, arising from the survey, is that it helps top explain past issues.

“I knew I was different but I did not know why, so I felt relief (after the diagnosis) because I wanted to know the reason why,” said Ian Bradley.

Carol-Anne said the AS diagnosis enabled her to see the world differently, “Most of my anxiety and depression comes from a feeling that I cannot cope with society; from others feeling that I can be told off, whereas they can’t; and that I can be bullied, but not them. Now I recognize my inability to ‘be myself’ in front of other people because I mimic their behavior patterns and ways of communicating. This can be detrimental to those closest to me and I don’t like myself for doing it. I want to take positive steps to find people who don’t make me feel like that, and who make me feel special as I am.”

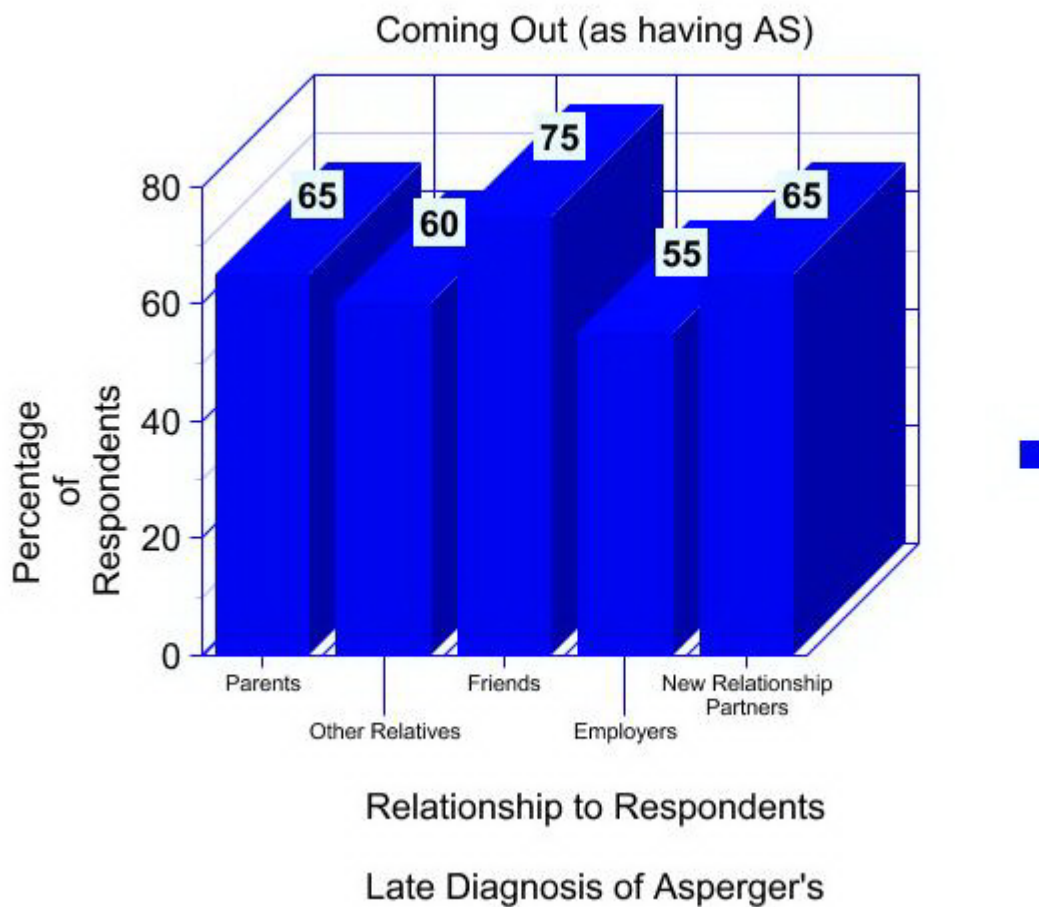
“All my prayers have been answered. I am annoyed with the psychiatrist for not helping me (long ago), but also surprised, because Mum is understanding me better now, so she is more relaxed with me now,” says Mark Lydon.

Fred Smith said that he felt relief initially, ‘although lately I have felt quite confused and bewildered by my situation’. Fred received his diagnosis last year, in 2012.

Jennifer Marks experienced shock initially, although she already suspected she had AS.

Coming Out

Whether to tell your parents, friends, employers, or potential relationship partners about your recent diagnosis is an important matter because it can influence your future a lot. One of the main traits of people with Asperger's syndrome is their will to tell the truth and uphold justice whenever possible. Some people with Aspergers' syndrome are so zealous and honest to the point that they are unable to tell even white lies (and this is an issue, which can cause many arguments).



Some adults with Asperger's syndrome may feel uncomfortable sharing their diagnosis with family members who are very conservative, elitist, perfectionist, controlling or bigoted. Such family members, who may even have Narcissistic Personality Disorder, lack affective empathy, so could delight in their son's (or daughter's) suffering.

"I've nothing to hide. I am what I am."

- John Carlisle

Adults with Asperger's syndrome have older relatives; and older people are less flexible in both mind and body. Some family members may be willing to accept the

diagnosis, but they may not be accepting of it as a family issue due to the acknowledged genetic links with autism. However, many of the respondents' parents were not alive during this survey.

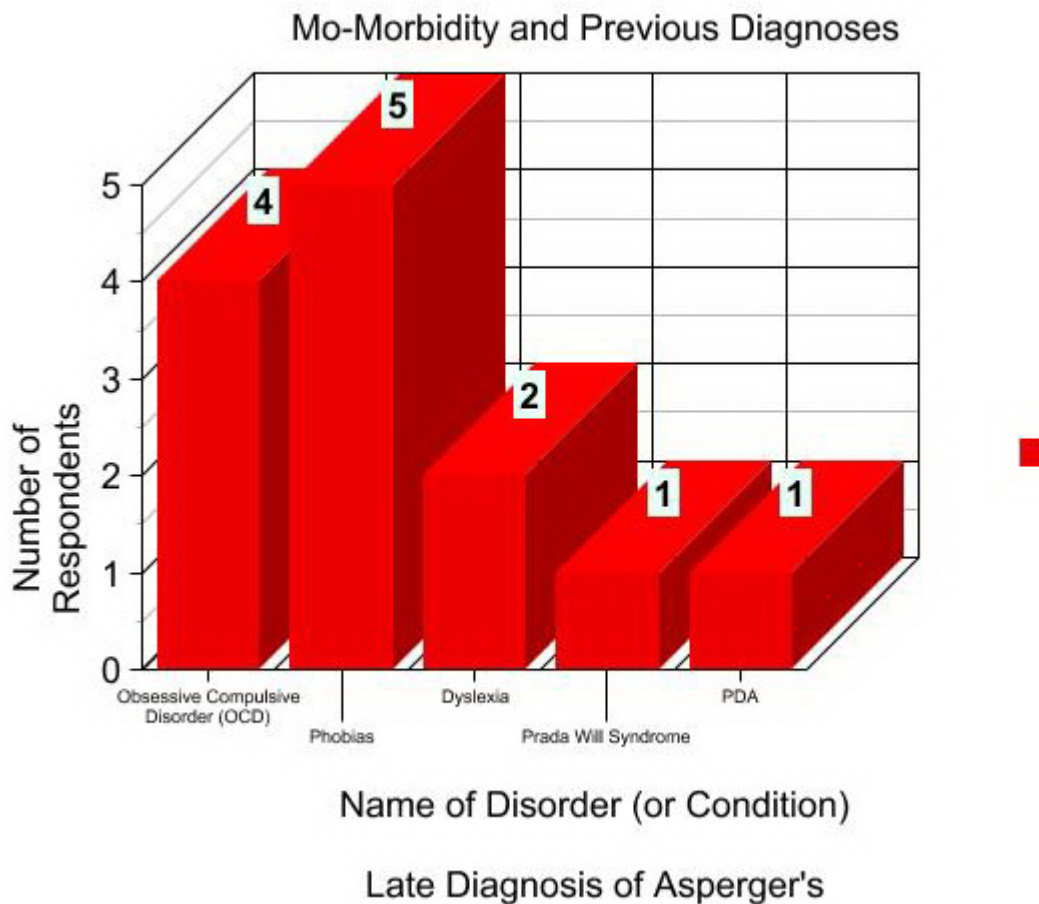
We asked the question: would you tell your employer about your diagnosis when you apply for a job? This rhetorical question can often have no clear answer but some of our respondents show many strengths that come with having Asperger's, which can benefit a future employer (without necessarily using the AS label).

Our question about telling future relationship partners about their AS was revealing as some women seek wealth and status in their male mates, but they would not find these qualities in many of the Aspergic men in this study.

Eric Middleton, who claims that he has never had a successful relationship, says he would not tell potential relationship partners about his AS condition. Unfortunately, it is very difficult for many unemployed autistic men to find suitable relationship partners.

CO-MORBIDITY AND MENTAL HEALTH ISSUES

The adults in this survey received the following diagnoses previously, but some of these diagnoses are invalid.

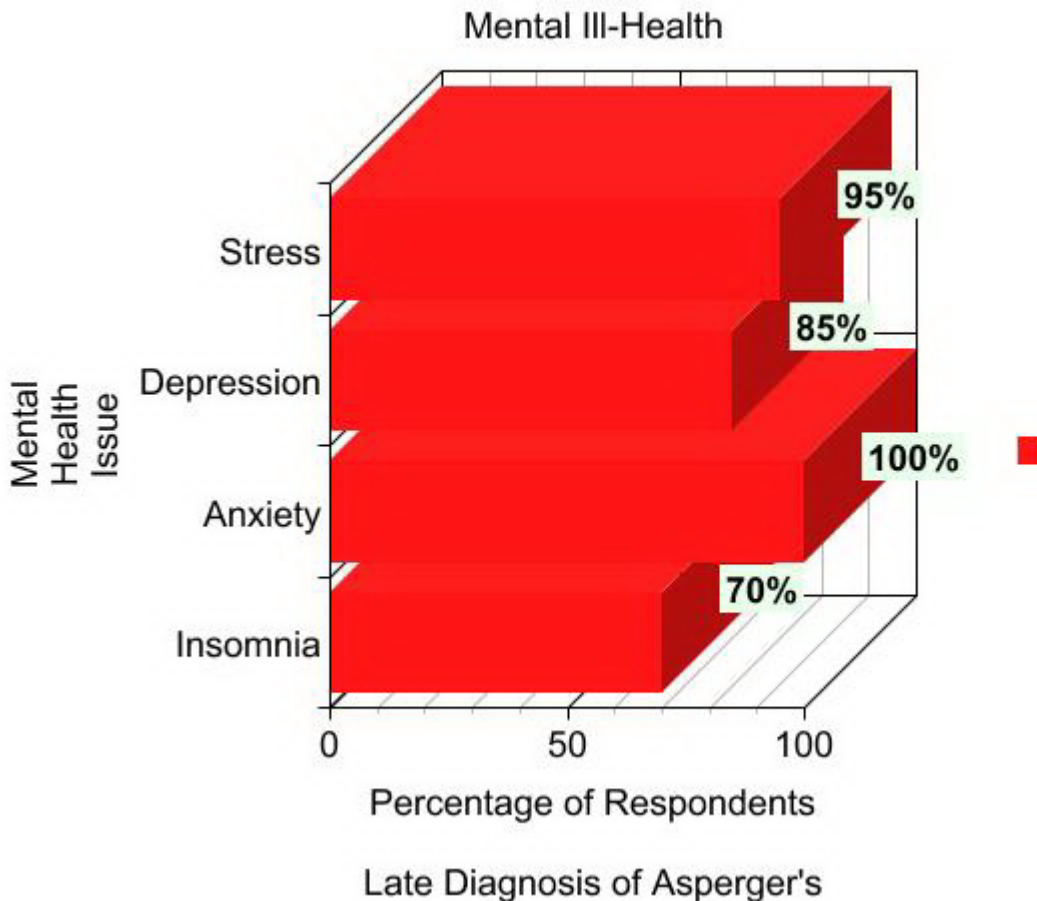


This autism survey clearly shows the damage – physical, emotional, mental, economic, and in all relationships – that can be caused by lack of appropriate support for these individuals in adulthood. The adult with Asperger's syndrome's self-esteem seems to diminish while his portfolio of mental issues grows.

Mental Ill-health

Mental ill-health is common in adults with Asperger's syndrome who are diagnosed late in their lives because it is thought that they have been struggling to survive using intellect instead of intuition and instinct in a neurotypical environment.

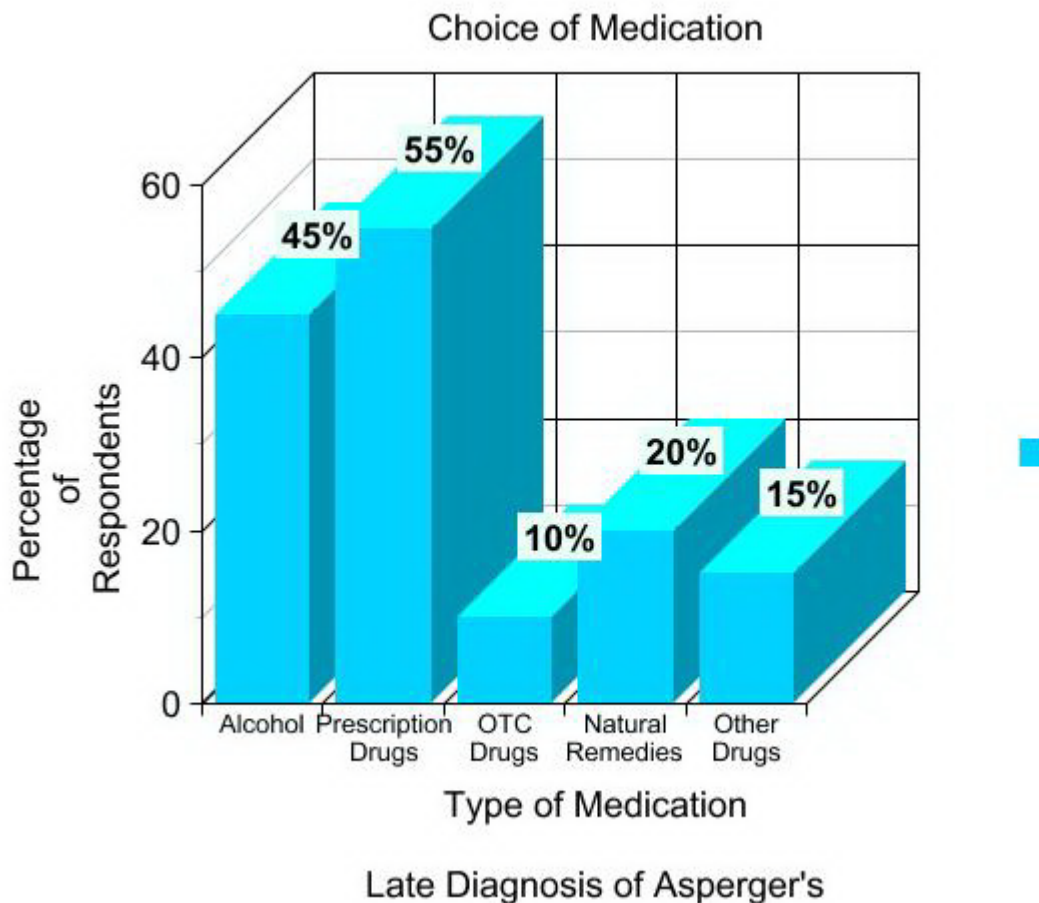
In this study, 100% of the respondents stated that they suffer from anxiety.



In addition to the above-stated mental health issues, 70% of respondents mentioned have anger management issues. Moreover, 50% of respondents disclosed that they have been arrested by the Police, or had other involvement in the criminal justice system.

It is often agreed that poor mental ill-health may be a costly consequence of not being diagnosed during childhood and receiving appropriate support. Due to their ability to mentally “catalogue” past hurts and trauma, when an adult with Asperger's syndrome is bullied, abused, or encounters relationship or employment issues, his/her mental health (including self-esteem) can tend to be adversely affected.

Medications



20 percent of the respondents say that they do not take any form of medication.

The most popular prescription drugs were anti-depressants (including Venlafaxine and Fluoxetine) and Selective Serotonin Reuptake Inhibitors (SSRIs), such as Escitalopram (Cipralex brand) and Citalapram. Other prescription drugs used by respondents include Prosurin XL to treat enlarged prostate glands and benign prostatic hyperplasia, Diazepam to treat anxiety, and Omeprazole to treat excess acid in the stomach.

Alcohol was used as self-medication (which is often used as a social lubricant and to combat social anxiety) by 45% of the survey respondents. The main benefit of alcohol is that it is accepted and legally available without prescription.

Over-the-counter (OTC) drugs cited by respondents include vitamin tablets, Paracetamol, and other tablets for headaches and indigestion.

The natural remedies used by respondents include 5HTP, Passiflora, fish oil and EHB.

15 percent of respondents have used other drugs including cannabis, cigarettes, and cigars.

Self-Harm and Suicidal Thinking

A massive 80% of the survey respondents admitted to suicidal thinking, and 50% had engaged in self-harm (including intentional self-mutilation, self-poisoning and self-injury). These statistics demonstrate the probable desperation of an excluded class of people who have a hidden intellectual disability.

“Lots of tablets in front of me My mate stopped me.”

- Phil Downing

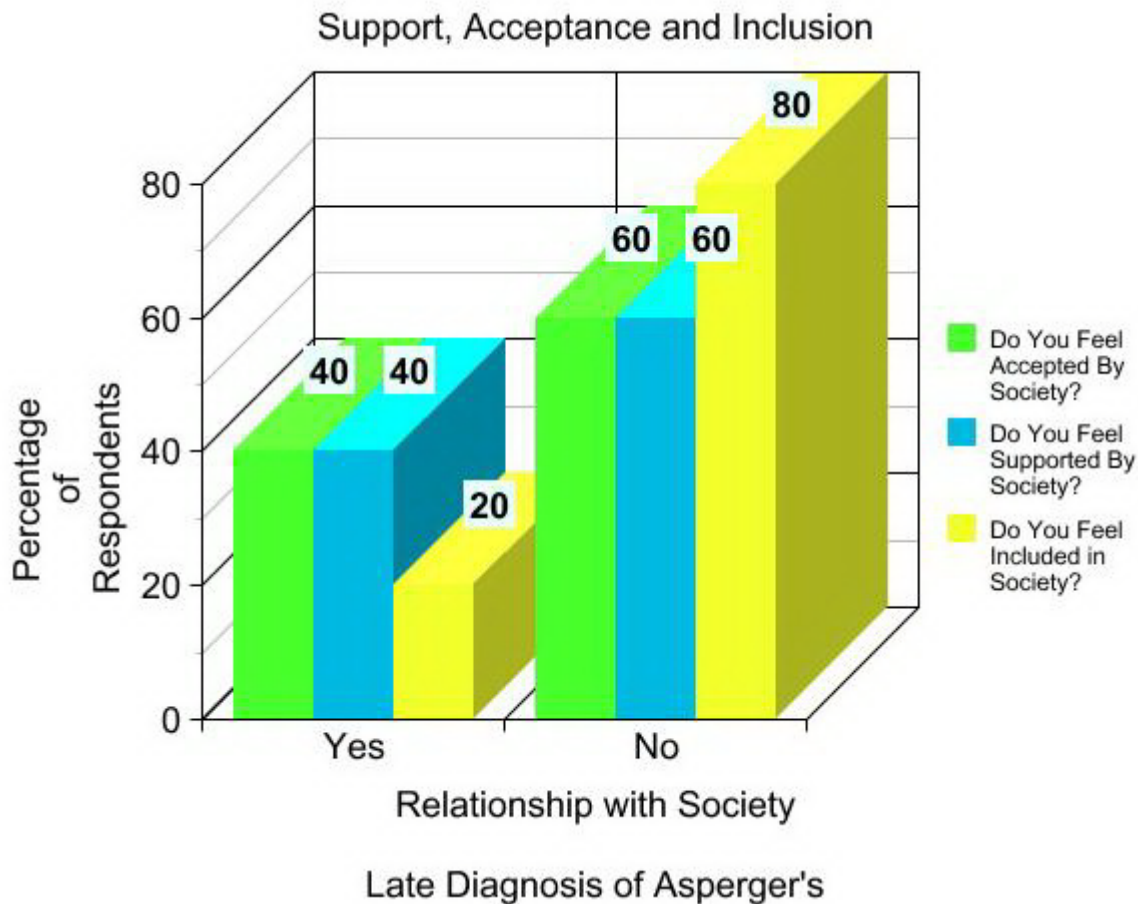
It's important to be aware that adults with Asperger's syndrome tend to be highly logical beings, so it is understandable that so many consider suicide when they cannot see a way out of their problems.

“Often use ligatures* ... I nearly threw myself off the roof of a car park.”

- Ian Bradley

* A ligature consists of a piece of thread tied around an anatomical structure, usually a blood vessel, to prevent the blood flow.

EXCLUSION BY SOCIETY



Ben Smith says that he feels accepted by his sister and family, other adults with Asperger's syndrome (from the self-help group) and his Mental Health support workers. However, Ben does not feel included in society. "I am left on my own day after day. I am rejected," he says.

"I feel isolated in the community, not believed by the establishment, and the Benefits officers don't believe me because I look normal. My sister, who also has an AS diagnosis, understands me, but I feel excluded everywhere else."

- Eric Middleton

Single mother Jane Short feels both accepted and included in society, but she is concerned about the lack of awareness among the lay public about Asperger's syndrome.

Ian Bradley feels accepted by fellow "Aspies" in his support group, but he says, **"I have never received the support I need. I have always felt excluded like an outcast."**

Ken Roberts, who feels neither accepted, supported, nor included in society, says, **"I don't feel the support I have received is effective, structured or informative.... so, I have isolated myself."**

Carol-Anne says, “There are very, very few women who think like I do. I am not interested in fashion or ‘going out for a laugh’. The ones who I have remained friends with - wait for it - either have had a late diagnosis too, or also have a child with ASD. That is not inclusion.”

Carol-Anne’s severely autistic brother is not safe on his own in public because he tends to stare at people. Carol-Anne’s family identified his autism after watching the movie ‘Rain Man’ with Dustin Hoffman.

Mark Lydon, who feels like an outcast, says he has been in prison three times, but has no idea why. On such occasions, he was beaten up, and once he was even sexually abused by a woman. Mark says, “I am always being accused of harassment, staring at people, making mistakes, and doing things that are (supposedly) unacceptable.”

SUMMARY AND RECOMMENDATIONS

It is clear from this survey that many adults with Asperger's syndrome need much more support than they are currently receiving. It is felt that most support is directed towards autistic children, so the population of undiagnosed adults has been left to "bungle" through their lives, often alone and with minimal support.

Autism is a complex condition, so adults with Asperger's syndrome are especially complicated due to the link with mental health, self-harm, self-medication and the person's ability to hide the syndrome, as well as their use of intellect to cope with social situations. Consequently, as evidenced by this survey, many diagnoses for adults on the autism spectrum are either incorrect or misleading (particularly when there are associated mental health issues). Therefore, we believe that diagnosis of autism is more effective when provided by full-time autism specialists; there is also a need for comprehensive awareness training about autism for the general public.

This survey indicates that society is prejudiced towards autistic people, although organizations such as the National Autistic Society and Autonomy are working hard to redress this imbalance. We support the social model of autism and we believe that adults with Asperger's syndrome should not feel afraid to admit their condition to anyone. We want routine screening for autism for people who are over 40 whenever they are referred for common mental health conditions, such as anxiety and depression. We also want to see "everyone talking about autism" with open recognition and acceptance of autism instead of the condition remaining stuck in the domains of medicine, psychiatry and mental health.

We feel that since there is no effective 'cure' for autism, society needs to be more tolerant of diversity and accepting of different types of human being. From the experiences of Autonomy's clients, it seems that prejudice and abuse exacerbates their depression and anxiety, so society sadly loses the skills and talents of our valued and committed Aspergic individuals.

APPENDIX 1: RESPONDENTS' PROFILES

Please note that each of the names of the following profiles have been changed to protect the respondents' identities.

Jennifer Marks is a 66-year-old divorced mother, who is not currently working, but who was employed as a Medical Personal Assistant. Jennifer loves cats, gardening and nature, literature and poetry, history, art, singing and music, writing and psychology.

Harry Lloyd is a 57-year-old pan-sexual man, who is currently in a relationship, and works as a telephone engineer. Harry enjoys documentaries, science and technology, and collecting watches and other interesting things.

John Carlisle is a 50-year-old divorcee who has children. John is not working currently, but he has worked as door attendant, foundry worker, lecturer, martial arts teacher, musician, and poet. His hobbies and interests include horror, sci-fi and fantasy movies and books, comics and novels. John also enjoys creative writing and music.

Robert Henley is a 61-year-old man who lives alone. Robert has a university degree and currently works as a volunteer. His main interests are history, walking, yoga and travel.

Phil Downing is a 46-year-old man who is in a relationship. Although Phil is not working at present, he has worked as bouncer, door attendant, scrap metal collector, and nightclub employee. Phil likes fish, dogs, crabs, and non-fiction such as nature programs (rather than science fiction).

Peter North is a 49-year-old divorcee with no children. Peter is not working and he was only employed as a window cleaner for a week and as a car washer for one day. Peter enjoys football, sports, Liverpool FC, sixties music and going out for drinks.

Debra Williams is a 41-year-old single mother. Although Debra is not working now, she was employed in a factory. Debra loves spending time with her daughter, spending money, and collecting things.

Chris Stevens is a 44-year-old single father who has had two long-term relationships. Chris is not currently working, but was employed in catering, warehouses, and call centres, in UK and overseas. Chris enjoys literature, research, fishing, history, archeology, cooking, and learning about the Knights Templar.

Ben Smith is a 51-year-old single man who has never been in a relationship. Ben did not pass any exams at school. When Ben worked in engineering and clerical jobs, he became too ill due to stress. Ben enjoys sci-fi (including Star Trek), comedies, and spy dramas.

Eric Middleton is a 42-year-old single man who admits to being very unsuccessful in relationships. Eric tried working in a job once, but he was bullied so much that he has not been able to work again since. Eric's main interests are poetry, Goth, wordplay, Greek mythology and "the furies".

Jane Short is a 40-year-old single mother who works as a self-employed dyslexia consultant and trainer. Jane's enjoys spending quality time with her son, and learning about dyslexia.

Ian Bradley is a 46-year-old single man who is currently in a relationship. Although Ian is currently working, he was employed as an odd job man, car park attendant, and cleaner. Ian is interested in money and finance, animals, gadgets, watching DVD's, and learning new skills on television.

Ken Roberts is a 42-year-old single man without any children. Ken has a food business, which he runs on a self-employed basis. Ken says he does not have any special interests nowadays because he is occupied with his business!

Brad Bentley is a 55-year-old single man with no children. Although Ken is not working at present, he was employed as a labourer, packer, part-time storeman, engineer and also at his local nursery. Brad is interested in art, horticulture, and photography.

Carol-Anne is a 39-year old single mother with two daughters and a son. Carol-Anne provides freelance accountancy services for legal firms in her area. Her main interests are mathematics, science, psychology, post-apocalyptic survival, and hiding from

people!

Mark Lydon is a 44-year-old single man. Mark is not currently working, but he has had several casual jobs such as cleaning and paint spraying. Mark enjoys keeping fit by boxing, cycling, and weight training. He loves the Rocky Horror Show movies and helping with his family's chores.

Fred Smith is a 42-year-old married man, who did not complete his university degree. Fred works as a cinema usher, invigilator, and support staff for his local arts centre. Fred enjoys writing, recording and performing music, martial arts, and learning about ancient history, astronomy, and mathematics.

Alan Ray is a 45-year-old married man with children. Alan has found his niche in IT and computers. Alan is interested in the internet, free software, veganism and animal rights, science fiction, and mycology (mushrooms and fungi).

Mike Philips is a 46-year-old former traveller, who is cared for by his previous relationship partner. Mike is not currently working, but he was employed as a security guard and had jobs in the scrap metal business. Mike is interested in travel and nature, particularly crabs and fish, his aquarium, weight training and spending time with his kids.

Tom Kidman is a 43-year-old single man with no children. Tom is not working presently, but he was employed at the Post Office, as a meat packer, dog walker, and as a volunteer. Tom's interests include computers, Facebook, cars, Manchester United, horror films, war games, model cars, and mobile phones.

APPENDIX 2: ABOUT PHILIP WYLIE

When I was younger, my parents used to tell me that I was selfish and ‘too honest’. Nearly fifty years later, these comments are highly significant to me. The word, Autism derives from the Greek word, *Autos*, which means ‘self’; so, Autism literally means being self-absorbed in our intellectual bubble.

Excessive honesty is a curse for many people with Asperger’s syndrome as it enables others to take advantage of us. For example, telling ‘white lies’ is a basic survival tool, as well as being a neurotypical ‘social skill’. An example is telling your spouse that her new hairstyle looks beautiful, when it looks ridiculous. This seemingly simple ‘skill’ is not so easy for AS people.

Later, when I studied energy medicine, several people told me that I was ‘ungrounded’. Most AS people are ungrounded because we are self-absorbed intellectuals without the basic instinct to survive using intuition. Emotions can be very confusing, so we depend on our logical thinking in a highly irrational world, but surviving by intellect alone causes mental exhaustion and anxiety.

I have been living in two different worlds for many years. I inhabit my own world when I am being my natural self, which may appear eccentric. On the other hand, I inhabit the ‘neurotypical world’ when I need money or acceptance. So, I found it necessary to wear masks to survive in this confusing world, and such behaviour undermines our self-esteem.

I directed my energy towards academic study, believing that excellent exam results would ensure a good livelihood. I trained to be a Chartered Accountant and I was good at the job, but I collapsed under the stress of office politics. So, although I had the best training, I was unable to sustain a top job due to my condition.

I was unable to survive in England as a Chartered Accountant, so I liquidated my possessions to live in Northern Thailand. In foreign cultures, quirky behaviour is simply perceived as ‘being foreign’, so I am treated better in this part of the world.

Since I became aware of my Asperger’s, my values have changed. Confusion and rebelliousness has given way to a deep need for self-acceptance and intent to help others who also have autism. I have no idea whether I can survive much longer, but I want to see my two beautiful Norwegian daughters again, if possible.

Finally, I want to suggest that the medical profession accept people on the autism spectrum as potentially healthy human beings, instead of disordered sick people who have nothing to offer society. People with autism have many abilities and they are usually able to concentrate on detailed information for a long time. However, for society to take advantage of these abilities, we need full understanding and support;

and our differences must be accepted.

Let's accept a world of diversity and drop the notion of forcing everyone to act the same.

APPENDIX 3: ABOUT SARA HEATH & AUTONOMY

Sara Heath, Cert. Ed., Adv. Cert, Post Grad Cert, M.Ed

Sara has a Master's Degree in Special Needs and Autism, and postgraduate qualifications in Dyslexia and Social Enterprise. She has been a teacher and lecturer in the area of learning disabilities and autism for over thirty years, and has expertise in High Ability Autism and Asperger's Syndrome. Sara is the mother of Eric, a young adult with Asperger's syndrome, and has personal experience of the benefits and challenges of having a son with this condition.

Sara and Eric set up the Autonomy self-help and social group for local young people and adults with Asperger's syndrome in 2004. Autonomy is the main provider of low-level support and advice about Asperger's syndrome in Telford, Shropshire and the Borderlands. The social enterprise Autonomy, which is free to join, has grown from strength to strength. The organisation is self-funded and provides a range of group activities, which are often attended by over 30 members, and includes a vibrant and well-attended women's session.

Sara is an independent consultant, specialising in low-level preventative interventions, advocacy and support along the autism diagnostic pathway, and post-diagnostic mentoring and coaching. She also runs training sessions on autism spectrum issues through AutonomyPlus with "lived experience" trainers, including her unique 'Women with Asperger's syndrome', 'Autism and Mental Health', and 'Autism and Criminal Justice' with anecdotes from her continuing professional practice.

APPENDIX 4: KEYWORDS, TERMS AND ABBREVIATIONS

Keywords

Autism, Aspergers, Asperger's syndrome, late diagnosis of Asperger's, depression, anxiety, OCD, Obsessive Compulsive Disorder, Philip Wylie, Sara Heath, the National Autistic Society, 2013 Asperger's survey, misdiagnosis of Aspergers, medication, self-diagnosis

Terms and Abbreviations

AQ test – Autism Quotient test

Obsessive Compulsive Disorder (OCD)

Pathological Demand Avoidance (PDA)

OTHER PUBLICATIONS

Very Late Diagnosis of Asperger's Syndrome (VLDAS)

Author: Philip Wylie

Publisher: Jessica Kingsley Publishers

Publication date: December 2013

Information: www.philipwylie.com/VLDAS/

The Nine Degrees of Autism: A 9-Step Model for Wellbeing

Author: Philip Wylie

Publication Date: September 2013

Information: www.philipwylie.com/publications/9degrees/

Philipwylie.com

www.shropshireautonomy.co.uk

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